Research Article

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# Communicating with Biobank Participants: Preferences for Receiving and Providing Updates to Researchers

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## Abstract

**Background:** Research biobanks collect biologic samples and health information. Previous work shows that biobank participants desire general study updates, but preferences about the method or frequency of these communications have not been explored. Thus, we surveyed participants in a long-standing research biobank.

**Methods:** Eligible participants were drawn from a study of patients with personal/family history suggestive of Cowden syndrome, a poorly recognized inherited cancer syndrome. Participants gave blood samples and access to medical records and received individual results but had no other study interactions. The biobank had 3,618 participants at sampling. Survey eligibility included age $\geq$18 years, enrollment within the biobank's first 5 years, normal *PTEN* analysis, and contiguous U.S. address. Multivariate logistic regression analyses identified predictors of participant interest in Internet-based versus offline methods and methods allowing participant–researcher interaction versus one-way communication. Independent variables were narrowed by independent Pearson correlations by cutoff $P < 0.2$, with $P < 0.02$ considered significant.

**Results:** Surveys were returned from 840 of 1,267 (66%) eligible subjects. Most (97%) wanted study updates, with 92% wanting updates at least once a year. Participants preferred paper (66%) or emailed (62%) newsletter methods, with 95% selecting one of these. Older, less-educated, and lower-income respondents strongly preferred offline approaches ($P < 0.001$). Most (93%) had no concerns about receiving updates and 97% were willing to provide health updates to researchers.

**Conclusion:** Most participants were comfortable receiving and providing updated information. Demographic factors predicted communication preferences.

**Impact:** Researchers should make plans for ongoing communication early in study development and funders should support the necessary infrastructure for these efforts. *Cancer Epidemiol Biomarkers Prev; 24(4); 708–12. ©2015 AACR.*



## Introduction

Research biobanks are collections of biologic materials and health information that are stored for on-going and future biomedical research. In contrast with research studies where patients routinely interact with investigators, participation in a research biobank is often limited to a single encounter. Once collected, biomaterials may be used for decades without further interactions with sample donors.

Bioethicists have voiced multiple concerns about the idea of biobank users having limited interactions with participants. Some have criticized biobanking practices that seek one-time permission for all future sample uses (1). Another source of controversy has involved recontact of participants to share findings of clinical significance. To date, debates about the importance of maintaining communication with biobank participants have focused largely on ethical and practical considerations related to the return of these individual research results when certain criteria are met (2–7). Existing guidelines on this subject are especially germane to biobanks involving genetic testing, where studies may identify genetic variation conferring increased risks for cancer or other diseases for which return of research results could eventually lead to changes in patient management.

Recontacting biobank participants about clinically relevant individual results may provide avenues for researchers to share aggregate results and study updates. Although the financial costs may appear prohibitive (3), the potential benefits to participants and researchers alike may provide motivation to proceed. Studies examining biobank participants' preferences about ongoing communication have shown that many want to receive regular updates about research done using their samples (8–10). The provision of such updates has been seen by bioethicists as a way to demonstrate respect and gratitude to study participants and increase their trust in the research enterprise (10). Regular communication with participants could also benefit researchers by providing opportunities to

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update their clinical datasets. However, studies to date have not explored biobank participants' preferences about what form these communications should take.

To explore these issues, we surveyed participants in a protocol-driven research biobank at the Cleveland Clinic (Cleveland, OH). The aims of our study were: to ascertain whether participants would like to receive study updates from researchers; to describe the methods and frequency of communication participants prefer; and to identify potential concerns that biobank participants may have about ongoing research communications. Our findings clarify which approaches are consistent with biobank participants' preferences about ongoing communication with clinical researchers.

## Materials and Methods

### Biobank population

The study sample was drawn from participants in a large biobank at Cleveland Clinic (IRB #8458). Biobank participants were enrolled because of personal and/or family history of cancer raising concern for Cowden syndrome, a rare hereditary condition predisposing to breast, thyroid, and other cancer types (11). This study began in 2005 and continues to enroll patients. After informed consent, blood is drawn, DNA and other biomaterials extracted and banked, and immortalized cell lines created. For participants who agreed to receive results, individual results deemed clinically relevant were relayed through the patient's enrolling health care provider. Unless there was concern with the consent process or need for sample redraw, participants did not have additional interactions with the biobank study team.

The biobank had 3,618 participants at the time of sampling. Eligibility for participation in the survey study described in this paper included: biobank enrollment within its first 5 years, age 18 years or older at enrollment, negative (normal) *PTEN* mutation analysis, complete contact information to allow for survey mailing, and contiguous U.S. residency. Participants were selected for negative *PTEN* results given that those with identified mutations had received direct individual benefit from study participation and many had repeated interactions with the clinician scientists on the study team. Applying these criteria produced a sample of 1,531 eligible individuals.

### Survey content

The survey was developed by an interdisciplinary team trained in bioethics, public health, and genetics. Questions were developed to gather data on the following domains: recall of study participation; experiences and beliefs about study participation; preferences about methods and frequency for receiving updates from researchers; preferences for providing updates to researchers; concerns about study participation; and demographics. Survey items were tested for readability and clarity within a small group of both genetic counselors and individuals with no formal training in genetics. The term "study updates" was chosen over "aggregate results" to maximize readability. The complete survey instrument is available upon request.

### Fielding

The research protocol and all study materials were approved by the Cleveland Clinic Institutional Review Board. A packet containing a cover letter, study fact sheet, survey, and self-addressed stamped envelope was sent to eligible participants by postal mail. A second packet was sent to participants who did not return a survey 8 to 10 weeks after the initial mailing. Survey fielding was open from January through August, 2012.

### Data management and analysis

Study data were managed using the REDCap electronic data capture platform hosted by Cleveland Clinic (12). Data entry was independently validated by a second research coordinator to ensure accuracy. Data were exported to SPSS Version 20 for statistical analysis. Univariate and bivariate analyses were done to characterize the data and to examine relationships between variables.

To further explore respondents' desires about the methods of communication, we examined their preferences related to two key features: use of Internet-based versus non–Internet-based communication methods, and whether a method of communication allows for one- or two-way participant/researcher interaction. To do so, we combined communication methods from researchers into the following subgroups: Internet-based (checking a blog or website, visiting an online discussion forum, becoming a fan of a Facebook page, following a Twitter feed, subscribing to a YouTube channel, receiving an emailed newsletter), non–Internet-based (receiving a paper newsletter, receiving a phone call, receiving an in-person update), methods only allowing for one-way communication from researchers (checking a blog or website, subscribing to a YouTube channel, receiving an emailed newsletter, receiving a paper newsletter), and methods allowing for participant/researcher interaction (visiting an online discussion forum, becoming a fan of a Facebook page, following a Twitter feed, receiving a phone call, receiving an in-person update). Similar subgroups were constructed to explore preferences about the methods of providing updates to researchers via Internet-based (sending an email or answering an emailed questionnaire, submitting a form via a website) or non–Internet-based (answering questions via telephone, mailing a questionnaire) methods. The Internet versus non-Internet outcome variable was analyzed by comparing survey respondents who indicated an interest in only receiving or providing updates through offline methods versus respondents who chose at least one Internet-based method. The one- versus two-way communication variable was created by comparing respondents who chose at least one method that allowed for participant/researcher interaction versus respondents who only chose methods that would not permit two-way communication.

To further examine these outcomes, two multivariate logistic regression analyses were performed to identify predictors of participant interest in (i) Internet- versus non–Internet-based methods of communication and (ii) methods of communication that allow for participant/research interaction versus methods that only allow for one-way communication from researchers to participants. Independent variables for regression analysis included demographic characteristics and other attitudinal variables that might be theoretically associated with desired methods of receiving general research updates. Variables for our logistic regression analysis were narrowed by independent Pearson correlations using $P < 0.2$ as the cutoff for inclusion. Multivariate logistic regression procedures were performed in SPSS version 20.0 (IBM-SPSS). Variables with $P < 0.02$ were considered to be significant predictors of preferences about methods of communication for receiving updates.

## Results

Survey packets were sent to 1,531 individuals. Of those, 188 were returned to sender, and 35 individuals were identified as deceased. After additional database review, 41 *PTEN* mutation positive patients were later removed from the data sample. Of the 1,267 eligible individuals who received the study packet, 840 (66%) completed and returned the survey.

Demographic characteristics of respondents are presented in Table 1. Most were female (96.4%), identified as non-Hispanic (96.7%) and white (94.4%). Their mean age was 58 years. Most had at least some college education and had higher than average household incomes. This demographic pattern is consistent with the population of this biobank as well as patients with high uptake of cancer genetics clinic referral (13). Responders were slightly older than nonresponders (57.7 vs. 55.2 years, $P = 0.05$).

Respondents' preferences for receiving general updates from researchers are presented in Table 2. Nearly all (97%) reported that they would like to receive general updates about the study with 92% wishing to be updated at least yearly. The most frequently selected methods of communication were receiving a paper newsletter (66%), receiving an e-mailed newsletter (62%), and checking a blog or website (30%). Nearly all respondents (95%) indicated that they would like to receive either an e-mailed or postal mail newsletter. The least preferred methods of communication for receiving study updates were becoming a fan of a Facebook page (8.9%), subscribing to a YouTube channel (6.1%), and following a Twitter feed (0.9%).

**Table 1.** Demographics of a sample of participants ($n = 840$) enrolled in a genetics biobank who completed a survey on preferences for communicating results from genetics research studies

| | |
|---|---|
| Age | |
| Mean age in y | 58.2 |
| SD | 11.0 |
| Range | 24–90 |
| | *n* (%) |
| Female | 810 (96.4) |
| Race[a] | |
| American Indian or Alaskan Native | 20 (2.4) |
| Asian | 12 (1.4) |
| Black or African American | 18 (2.1) |
| Native Hawaiian or Pacific Islander | 1 (0.1) |
| White or Caucasian | 793 (94.4) |
| Ethnicity[b] | |
| Hispanic or Latina/Latino | 27 (3.3) |
| Education[c] (highest completed) | |
| Some high school | 7 (0.8) |
| High school graduate or G.E.D. | 111 (13.4) |
| Associate's degree or vocational training | 108 (13.1) |
| Some college | 177 (21.4) |
| Bachelor's degree | 226 (27.3) |
| Graduate degree | 198 (23.9) |
| Annual household income[d] | |
| $19,999 or less | 39 (5.2) |
| $20,000–$49,999 | 145 (19.4) |
| $50,000–$74,999 | 160 (21.4) |
| $75,000–$99,999 | 124 (16.6) |
| $100,000 or more | 279 (37.3) |
| Patient seen by Cleveland Clinic providers | |
| Ever been a patient at Cleveland Clinic[e] | 78 (9.4) |
| With a genetic counselor or geneticist[f] | 64 (82.1) |
| With physician who is the researcher of the genetic study[g] | 48 (75.0) |

[a] $n = 826$. Some respondents indicated more than one race.
[b] $n = 824$.
[c] $n = 827$.
[d] $n = 747$.
[e] $n = 830$.
[f] $n = 78$.
[g] $n = 64$.

To understand whether demographic variables or other responses might predict preferred methods to receive updates, we compared respondents who chose one or more Internet-based methods (584/840, 70%) as opposed to respondents who chose only non-Internet methods (256/840, 30%). Age, income, and education emerged as statistically significant predictors ($P < 0.01$) of preference for only non–Internet-based methods, with older, less educated, and lower-income respondents more likely to prefer solely offline approaches. We also used logistic regression to predict which respondents would prefer a method of communication that would allow for interactive or two-way communication between researches and a participant as opposed to methods that would only allow for one-way communication from a researcher to a participant. Thirty-nine percent ($n = 327$) of respondents opted for at least one method that would allow for two-way communication between the researcher and participant. Desired frequency of receiving updates ($P = 0.004$) and views on the importance of being able to ask researchers questions ($P < 0.001$) were predictive, with respondents who wanted more frequent updates and who placed a higher level of importance on being able to ask researchers questions being more likely to choose interactive methods (Table 3).

Several survey items examined potential concerns about receiving study updates. Most respondents (88%) stated that they had no concerns about getting regular updates from researchers. Fifty-seven (7.1%) chose one or more potential concerns from a list of options. Among the 57 respondents who noted at least one concern, just over half ($n = 29$, 51%) were concerned that receiving study updates might cause them to worry about their health, and 25 (44%) were concerned that receiving study updates might reveal their study participation to others. Having concerns about receiving study updates was not associated with any demographic variable (Pearson $\chi^2$, $P > 0.05$) but respondents who noted concerns were less likely to want any study updates (Pearson $\chi^2$, $P < 0.001$).

Sixty-two percent of respondents indicated that it was important to receive study updates in a way that kept their participation private. These respondents did not differ from others with respect to preferences for Internet-based versus non–Internet-based methods (Pearson $\chi^2$, $P > 0.05$) but were less likely to prefer communication methods that would allow for two-way interaction with researchers (Pearson $\chi^2$, $P = 0.02$).

Nearly all respondents (97%) would be willing to provide health updates to researchers. The majority of respondents would prefer that researchers contact them to request updates (75%) rather than contacting researchers to provide updates whenever participants felt it was important (25%). Most (70%) indicated that they would be comfortable providing updates via a mailed questionnaire; many would also be comfortable using an e-mailed questionnaire (50%), website form (31%), or telephone (28%). Comfort with Internet-based methods was again associated with age, income, and education, with respondents who were younger, with higher income, and with higher education levels more likely to choose at least one Internet-based communication method (Pearson $\chi^2$ $P < 0.001$).

**Table 2.** Respondents' preferences for receiving general updates from researchers about the genetics research study in which they participate

| Preferences for receiving general updates from researchers | *n* (%) |
|---|---|
| Respondents who would like to receive general updates about the study | 801 (96.9) |
| Frequency of receiving updates ($n = 801$) | |
| I would like to be updated once every other year. | 62 (7.8) |
| I would like to be updated every year. | 508 (63.8) |
| I would like to be updated more than once every year. | 226 (28.4) |
| Method for receiving updates ($n = 801$) | |
| Receive a paper newsletter with updates on the progress of the study. | 526 (65.7) |
| Receive an emailed newsletter with updates on the progress of the study. | 494 (61.7) |
| Check a blog or website where updates are regularly posted. | 239 (29.8) |
| Receive a phone call from the researchers. | 213 (26.6) |
| Visit an online discussion forum run by the researchers. | 126 (15.7) |
| Receive an in-person update at an event hosted by the researchers. | 124 (15.5) |
| Become a fan of a Facebook page about this study. | 71 (8.9) |
| Subscribe to a YouTube channel about this study. | 49 (6.1) |
| Follow a Twitter feed about this study. | 7 (0.9) |

## Discussion

Biobanks are critical resources in the study of human health and disease. Although there have been calls to increase communications between biobank managers and sample donors (14), it is unclear which methods are most effective in achieving this goal and how frequently a large number of actual biobank participants would like to receive such updates. Furthermore, previous studies of participant attitudes about DNA biobanks have not examined whether participants would be willing to provide health updates to researchers and if so, what methods of sharing their personal health information would be viewed as acceptable. The results we report clarify which communication approaches are consistent with the expectations and preferences of actual biobank participants.

A major finding of our study is that the vast majority of biobank participants would like to receive regular study updates. Most wanted updates at least yearly and few expressed concerns about receiving such updates. Many participants would also welcome the opportunity to provide researchers with regular updates about their health status.

A second major finding of our study is that most biobank participants are comfortable with relatively inexpensive and convenient methods of communicating with researchers, such as yearly newsletters and emailed updates, and that these methods were acceptable to participants who placed high importance on receiving updates in a manner which kept their participation private. This finding suggests that the financial costs and other practical burdens associated with updating biobank participants about the use of their biologic materials may be limited. To ensure effective communication with participants, biobank developers should prepare long-term budgetary plans that provide appropriate staffing and other communication resources, and funders should be prepared to financially support these activities within research budgetary requests. It may also be appropriate to provide participants with options about receipt of study updates (both whether to receive and via what method) during the informed consent discussion.

It is noteworthy that a significant proportion of biobank participants prefers communication approaches that are bi-directional and allow them to ask questions about research that has been done using their biologic materials. This subset of participants was more likely to want more frequent research updates and might reasonably be categorized as participants who are more highly engaged in the research process. It may be useful for researchers to provide opportunities for more highly engaged research participants to learn more about studies that have been done using their biologic materials. For example, researchers might make peer-reviewed publications available to interested participants via study websites. Maintaining relationships with research participants who are highly interested and engaged in the biobank has potential to be beneficial to researchers, as these participants may have an interest in supporting projects in which they are involved and/or interested.

There are several limitations associated with the results we report. Our results are based on a single DNA biobank for protocol-driven heritable neoplasia syndromes and may not be generalizable to other research settings. Participants in our study were

**Table 3.** Logistic regression models predicting respondent preferences for receiving study updates from researchers

| Independent variable | Exp (B)/OR | *P* | 95% confidence interval |
|---|---|---|---|
| Outcome of interest: Non–Internet–based communication methods (1) vs. individuals selecting at least one Internet-based method of communication (0). | | | |
| Age | 1.03 | 0.001 | 1.011–1.046 |
| Income | 0.77 | <0.001 | 0.669–0.880 |
| Education | 0.72 | <0.001 | 0.624–0.840 |
| Research contact for updates vs. patient contact to give updates | 0.839 | 0.394 | 0.559–1.257 |
| Interest in participating in another genetic study | 0.832 | 0.117 | 0.661–1.047 |
| Recontact for permission to continue using sample | 0.912 | 0.614 | 0.639–1.303 |
| Outcome of interest: Preference for two-way communication methods (1) vs. individuals selecting no two-way methods of communication (0). | | | |
| Desired frequency of receiving updates | 1.51 | 0.004 | 1.14–1.99 |
| Importance of asking questions to researchers | 2.10 | <0.001 | 1.80–2.46 |
| Important that updates are returned in a way that protects privacy | 0.883 | 0.071 | 0.771–1.011 |
| Age | 0.991 | 0.262 | 0.977–1.006 |
| Recontact for permission to continue using sample | 1.17 | 0.334 | 0.846–1.639 |
| Interest in participating in another genetic study | 1.109 | 0.370 | 0.885–1.389 |

disproportionally female, white, highly educated, and had a high annual household income. Although this sample is not representative of the U.S. population, it is reflective of patients who accept referrals for cancer genetics evaluation (13, 15). We also acknowledge that the definition of "study updates" may have been interpreted differently by participants. Finally, given that the survey was sent via postal mail, we cannot know whether participants required or received assistance and input from others to complete it.

Beskow and colleagues have argued that providing aggregate results to study participants affirms the value of their contributions to research, results in greater awareness of the impact of clinical research, and supports public trust in the research enterprise (3). In addition to demonstrating respect for biobank participants, ongoing communication with research participants could have far-reaching benefits. Giving participants an opportunity to learn more about progress of the research they have contributed to may foster a greater sense of transparency among researchers and increase public trust in scientists. Enhancing the research experience of biobank participants may also promote study retention and willingness to participate in future studies. This is especially important for genetic research studies on rare diseases, not only to researchers but also to the patients and families who want to contribute to science and help in the development of new treatments.

Our results highlight the importance of ongoing communication with biobank participants and clarify which communication strategies are most consistent with participant preferences. The overwhelming majority of our survey respondents welcomed opportunities to receive and provide updates and had no concerns about these communications. These findings can assist researchers in developing communication plans that align with participant preferences without creating unnecessary costs or inappropriate burdens on researchers and biobank managers.

## Disclosure of Potential Conflicts of Interest

No potential conflicts of interest were disclosed.

## Disclaimer

The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

## Authors' Contributions

**Conception and design:** J.L. Mester, M.B. Mercer, A. Goldenberg, C. Eng, R.R. Sharp

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